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Table 1 Recent initiatives related to data and knowledge management in healthcare and biomedical research

Acronym	Website	Description
ACGT	Website not available (finished in 2010)	The Advancing Clinico-Genomic Trials on Cancer (ACGT) project was an open grid of services for improving medical knowledge discovery that aimed to developing open-source, semantic and grid-based technologies in support of post genomic clinical trials in cancer research. It addressed clinicians', bio-researchers' as well as software developers' needs, providing an open platform where novel and powerful services could be offered and used by practitioners in the field.
ACTION-Grid	http://www.action-grid.eu/ (finished in 2010)	ACTION-Grid is a specific international cooperation project on healthcare information systems based on Grid capabilities and biomedical informatics (BMI) between Latin America, the Western Balkans and the European Union. ACTION-Grid acted as a multiplier of previous outcomes in Grid and BMI, and disseminated these outcomes in Latin America, the Western Balkans and North Africa.
CPIC	http://www.pharmgkb.org/page/cpic	The Clinical Pharmacogenetics Implementation Consortium (CPIC) aims to address some of the barriers to implementation of pharmacogenetic tests into clinical practice. CPIC provides guidelines that enable the translation of genetic laboratory test results into actionable prescribing decisions for specific drugs.
DataSHIELD	http://ije.oxfordjournals.org/content/39/5/1372.abstract	The DataSHIELD project ('resolving a conflict in contemporary bioscience—performing a pooled analysis of individual-level data without sharing the data'), launched last year by Professor Michael Weiner of the University of California-San Francisco, has two goals: (i) to make widespread raw data sharing a reality — initially in the realm of medicine — through creation of a repository system accessible to all researchers; and (ii) to foster broad scientific support for this move and its adoption in other fields of research.
DebugIT	http://www.debugit.eu/	The goals of the Detecting and Eliminating Bacteria Using Information Technology (DebugIT) project are: (i) to contribute to world-leading levels of patient safety and risk management when applying antibiotics and combating resistance; (ii) to develop a globally useful, generically applicable eHealth system based on new tools (semantic information technology, text and data analytics) representing a fundamental advance throughstate-of-the-art computerized systems; and (iii) to thereby support healthcare providers at the hospital and community care level as well as public health officials at regional, national and global levels through better information and decision support on these issues.
DDMoRe	http://www.ddmore.eu/	Model based-drug development (MBDD) is accepted

		as a vital approach in understanding patient risk/benefit and attrition. At the core of MBDD lies modelling and simulation, a technology providing the basis for informed, quantitative decision-making. The core strategy of the Drug Disease Model Resources (DDMoRe) consortium is standards: a newly developed common definition language for data, models and workflows, along with an ontology-based standard for storage and transfer of models and associated metadata.
Dicode	http://dicode-project.eu/	The goal of the Dicode project is to facilitate and augment collaboration and decision-making in data-intensive and cognitively complex settings.
EHR4CR	http://www.ehr4cr.eu/	The Electronic Health Record for Clinical Research (EHR4CR) project is one of the largest public–private partnerships aiming at providing adaptable, reusable and scalable solutions (tools and services) for reusing data from electronic health record systems for clinical research.
EMIF	http://www.imi.europa.eu/content/emif	The European Medical Information Framework (EMIF) plans to address the challenges of developing a sustainable and scalable information framework which has the potential to access data on a scale and at a level of detail not currently available, which will completely re-shape the way researchers approach key scientific questions, and to open avenues of research that so far have been out of reach. The project combines generating a common patient health information framework with addressing two research topics: obesity and its metabolic complications, and markers for the development of Alzheimer's disease and other dementias.
eTOX	http://www.etoxproject.eu/	The eTOX project aims to develop innovative methodological strategies and novel software tools able to predict the *in vivo* toxicology of new molecular entities by means of information that is available in early stages of the drug development pipeline.
eTRIKS	http://www.etriks.org/	European Translational Information and Knowledge Management Services (eTRIKS) aims to create and run an open, sustainable research informatics and analytics platform for use by Innovative Medicines Initiative (and other) projects with knowledge management needs.
EU-ADR	http://www.eu-adr-project.com/ (finished in 2012)	The Exploring and Understanding Adverse Drug Reactions (EU-ADR) project aimed to develop an innovative computerized system to detect adverse drug reactions, supplementing spontaneous reporting systems. To achieve this objective, EU-ADR exploits clinical data from electronic healthcare records (EHRs) of over 30 million patients from several European countries (The Netherlands, Denmark, UK and Italy). In this project a variety of text mining, epidemiological and other computational techniques will be used to analyse the EHRs in order to detect and biologically substantiate 'signals' (combinations

		of drugs and suspected adverse events that warrant further investigation).
EUPATI	http://www.patientsacademy.eu/index.php/en/	The European Patients' Academy on Therapeutic Innovation (EUPATI) is a patient-led initiative that aims to develop the first, such academy with training courses, educational material and an online public library that will empower patients to engage more effectively in the development and approval of new treatments and become true partners in pharmaceutical R&D.
Gen2Phen	http://www.gen2phen.org/	The GEN2PHEN project aims to unify human and model organism genetic variation databases towards increasingly holistic views into genotype-to-phenotype data, and to link this system into other biomedical knowledge sources via genome browser functionality.
HVP	http://www.humanvariomeproject.org/	The purpose of the Human Variome Project (HVP) is to alleviate needless human suffering for many millions of the global population by collecting, organizing and sharing data on genetic variation. The HVP consortium is motivated by the knowledge that, by working together, we will be able to significantly reduce such needless physical, psychological, emotional and economic suffering.
Hypergenes	http://www.hypergenes.eu/	The Hypergenes project investigates associations between genetic variants and essential hypertension, in order to construct a rich disease model that would combine both clinical and genomic factors using genome-wide association studies. A semantic warehousing methodology was developed and implemented successfully for the integration and analysis of over 25 cohorts in the study, resulting in a biomedical information infrastructure, which includes a warehouse based on international standards with harmonized hypertension ontology, along with user-defined data marts for optimized analysis conducted by a bio-clinical data mining tool.
INBIOMEDvision	http://www.inbiomedvision.eu/	The general objective of INBIOMEDvision is to promote biomedical informatics by means of the permanent monitoring of the scientific state-of-the-art and existing activities, prospective analysis of the emerging challenges and opportunities, and dissemination of the knowledge in the field.
INTEGRATE	http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=8008	The Integrative Cancer Research Through Innovative Biomedical Infrastructure (INTEGRATE) promotes a novel information technology-based approach aimed at enabling multidisciplinary collaboration in oncology research. This will be achieved through: the creation of innovative biomedical infrastructures; emphasis on standards-based harmonization of efforts; the preservation, management and large-scale sharing of multi-level data; and the development of new methodologies and predictive multi-scale models in cancer.

ITFoM	http://www.itfom.eu http://itfom_portal.nakijken.nl/	The aim of IT Future of Medicine (ITFoM) is to lead the way towards truly personalized healthcare, exploiting the unprecedented amounts of detailed biological data for individuals, and turn this information into actual knowledge that helps in making medical and lifestyle decisions. ITFoM will construct computational models of the biological processes that occur in every human. Because everybody is different, the models will be tailored to each individual to reflect the unique anatomical, physiological and genetic makeup.
I4Health network	http://www.i4health.eu/	Integration and Interpretation of Information for Individualized Healthcare (I4Health) seeks to define and promote the concept and the methods of knowledge engineering for health, to properly connect research and medicine.
Khresmoi	http://www.khresmoi.eu/	Khresmoi is developing a multilingual multimodal search system for biomedical information and documents. This is being achieved by: (i) effective automated information extraction from biomedical documents, including improvements using crowd sourcing and active learning; (ii) automated estimation of the level of trust and target user expertise; (iii) automated analysis and indexing for medical images in two-dimensions (2D; X-rays), 3D [magnetic resonance imaging (MRI), computed tomography] and 4D (MRI with a time component); and (iv) linking information extracted from unstructured or semi-structured biomedical texts and images to structured information in semantically rich knowledge bases.
MDHT	https://www.projects.openhealthtools.org/sf/projects/mdht/	Open Health Tools Model-Driven Health Tools (MDHT) project is a wide-ranging open-source effort to promote interoperability in healthcare infrastructure. It promotes shared artifacts between related healthcare standards and standards development organizations, and works to develop localized specifications. It also delivers a common modelling framework and tools that support seamless integration of design, publication and runtime artifact creation. In particular, MDHT allows the creation of computable models of Clinical Document Architecture (CDA) templates in Unified Modeling Language (UML), along with Object Constraint Language (OCL).
OMOP	http://omop.fnih.org/	In partnership with Pharmaceutical Research and Manufacturers of America PhRMA and the Food and Drug Administration, the Foundation for the National Institutes of Health launched the Observational Medical Outcomes Project (OMOP), a public–private partnership. This interdisciplinary research group has undertaken a surprisingly difficult task that is critical to the research community's broader aims: identifying the most reliable methods for analysing huge volumes of data drawn from heterogeneous sources.
OncoTrack	http://www.oncotrack.eu/	The goal of OncoTrack is to identify and characterize

		biological markers that will help our understanding of the variable make-up of tumours and how this affects the way patients respond to treatment. Cutting edge laboratory-based genome sequencing techniques will be used, coupled with novel computer modelling approaches, to study both the biological heterogeneity of colon cancers (i.e. patient to patient variability) and tumour variation within the individual patient (e.g. by comparing primary tumours with metastases).
Open PHACTS	http://www.openphacts.org/	To reduce the barriers to drug discovery in industry, academia and small businesses, the Open PHACTS consortium is building an open pharmacological space. This will be a freely available platform, integrating pharmacological data from a variety of information resources and providing tools and services to investigate these integrated data to support pharmacological research.
Orphanet	http://www.orpha.net/consor/cgi-bin/index.php	Orphanet is the reference portal for information on rare diseases and orphan drugs, for all audiences. The aim of Orphanet is to help improve the diagnosis, care and treatment of patients with rare diseases.
Personalised Medicine	http://www3.marshfieldclinic.org/chg/pages/default.aspx?page=chg_pers_med_res_prj	The goal of the Personalised Medicine project is to learn how to apply genetic science to human health. This knowledge will help researchers develop new medications and diagnostic tests, and will enable physicians to prescribe medications that work best for each individual.
PharmaCog	http://www.alzheimer-europe.org/Research/PharmaCog	The PharmaCog project aims to develop and validate new tools to test candidate drugs for the treatment of symptoms and disease in a faster and more sensitive way. By bringing together databases of previously conducted clinical trials and combining the results from blood tests, brain scans and behavioural tests, the scientists will be able to develop a 'signature' that gives more accurate information on the progression of the disease and the effect of candidate drugs than current methods do.
PHGEN	http://www.phgen.eu	Public Health Genomic European Network (PHGEN) aims to produce the first edition of "European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies". Example of their activities: the GRAPH-Int network (http://www.phgen-meeting.eu/programme/graph-int) is the leading voice at the global level in the field of public health genomics and personalized healthcare. It bridges the translation process from basic research to policymaking and practice, and facilitates 'push–pull' functions between academia, governmental bodies and the private sector.
PHIS	http://whocc.goeg.at/ (finished in 2011)	The aim of the PHIS project was to increase the level of knowledge and exchange of information on pharmaceutical policies in the European Union. It was envisaged that this would be achieved by surveying and monitoring pharmaceutical health system

		information in the inpatient and outpatient sector from a public health perspective, and by developing key pharmaceutical health indicators to be included in a European health information system.
p-medicine	http://www.p-medicine.eu	The p-medicine consortium aims to create support and sustain new knowledge and innovative technologies to overcome current problems in clinical research and pave the way for more individualized therapy.
preDICT	http://www.vph-predict.eu (finished in 2011)	The Predicting Drug Effects on the Hearth (preDiCT) project officially began in June 2008, with a 3-year mission to model, simulate and ultimately predict the impact of pharmacological compounds on the heart's rhythm using computer models.
TranSMART	http://www.transmartproject.org/	TranSMART is a knowledge management platform that enables scientists to develop and refine research hypotheses by investigating correlations between genetic and phenotypic data, and assessing their analytical results in the context of published literature and other work.
VAESCO	http://vaesco.net/vaesco.html	The Vaccine Adverse Event Surveillance & Communication (VAESCO) network aims to develop guidelines and a sustainable infrastructure for post licensure vaccine safety assessment in the European region.
VPH NoE	http://www.vph-noe.eu/	The Virtual Physiological Human Network of Excellence (VPH NoE) is an EU-funded network that aims to help support and progress European research in biomedical modelling and simulation of the human body. This will improve our ability to predict, diagnose and treat disease, and have a dramatic impact on the future of healthcare and the pharmaceutical and medical device industries.